

ORGANIZATION OF DIAGNOSTIC
AND TREATMENT CLINICS FOR
CEREBRAL PARALYSIS IN DENMARK

A SUBCOMMITTEE OF THE DANISH SOCIETY OF
CHILD NEUROLOGISTS

1980

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NOTES

It is with pleasure and relief, as well as hope that it will prove useful, that this supplement is now presented.

Although it is as short and succinct as we could make it, we have tried to cover all aspects of diagnosis and treatment. This is why we have been so busy in producing so small a volume—we have had to argue and disagree, and have many more thoughts. Our many discussions have highlighted the great problems for cerebral pained children and their parents, and for those who are professionally concerned: the constant examination, the enormous number and variety of ignorance involved, the need for inter-professional understanding and co-operation.

My personal thanks are due to the volunteers for the way they have created and created the booklet, and I must express the gratitude of the community to Mrs. M. J. Anderson for bringing her fresh and busy mind to bear on the work we thought was done. She has rearranged the material so that the final presentation is as clear as possible and more intelligible. Our thanks are also due to the authors who have been working about various sections.

David L. Galt

INTRODUCTION

1. The cerebral pained child needs enough early done:

(a) a complete diagnosis covering general health, mental, sensory, speech, intellectual, social and emotional aspects.

(b) all the types of treatment necessary to help him to obtain his best possible in the minimum, so that he may enjoy the greatest degree of independence possible.

(c) a social setting, mainly at first his family, which will give him love and security necessary for the maximum growth and development of his personality.

(d) education specially adapted to his mental handicap and such to those who understand his condition, so that he may use his development to its fullest extent.

(e) when he is old enough, an opportunity for vocational and social contacts with others of his own age, with sympathetic understanding and, wherever possible, treatment as a normal individual.

2. The understanding and co-operation of the child's parent should be secured by every possible means. The child should be helped to become and remain well adjusted

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FOREWORD

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Norah Gibbs.

INTRODUCTION

1. The cerebral palsied child needs amongst many things:
 - (a) a complete diagnosis covering general medical, motor, sensory, speech, intellectual, social and emotional aspects;
 - (b) all the types of treatment necessary to help him to reduce his handicaps to the minimum, so that he may enjoy the greatest degree of independence possible;
 - (c) a social setting, usually at first his family, which will give him the love and security necessary for the maximum growth and development of his personality;
 - (d) education suitably adapted to his complex handicaps and needs by those who understand his condition, so that his mind can develop to its fullest capacity;
 - (e) when he is old enough, an opportunity for recreation and social contacts with others of his own age, with sympathetic understanding and, whenever possible, treatment as a normal individual.
2. The understanding and co-operation of the children's parents should be secured by every possible means. The child should be helped to become and remain well adjusted

within the family. Good parental care is clearly necessary, but parents themselves need different kinds and degrees of help. This varies from straightforward explanation of the child's condition, and its implications for treatment and education, to skilled and often prolonged help in accepting the child as he really is and as he is likely to develop. It is easy for the situation to become unduly emotionally conditioned, to the ultimate detriment of the medical and educational aspects of the physical handicap.

3. Constant care must be given to accurate assessment. As well as the general medical and neurological findings, estimates of the intellectual and emotional aspects of the cerebral palsied child are fundamental. Particular care is necessary to avoid errors which might prejudice the child's needs, especially those of education and welfare. It is essential that all those concerned in assessment should be able and willing to re-assess any child either because others have observed changes or because knowledge has increased or techniques have been refined. Ideally all assessment should be serial, in the interests both of the individual and of research.

The assessment of cerebral palsy is a complex problem and so a matter of expert knowledge, but enthusiasm and intelligent joint interest by teachers, physiotherapists, social workers and others engaged in the direct day-to-day care and treatment are necessary for success in helping these children.

4. Teachers and doctors have an indivisible interest and responsibility in all this work with physically handicapped cerebral palsied children, and, so that no gaps shall occur, an overlapping of function, as between the medical and the educational sphere, is a safeguard at all times.

In treatment and education, particularly difficult problems are presented by some severe athetoids of normal intelligence.

5. The treatment clinic for cerebral palsied children should be able to supply medical treatment, suitable educational facilities, physiotherapy, speech therapy and psychotherapy, where they are not available to children through the public educational system or health services.

6. Liaison with other bodies. At the moment the care of the cerebral palsied children may be undertaken by the local authority, the Regional Hospital Board or one or other of a number of voluntary bodies. There is a great wastage of work and resources owing to gaps in the care of some types of case and overlapping in the care of other types. It is hoped that in future fuller consultation between the various services will enable all facilities to be used to the greatest advantage.

Liaison is also important in the voluntary clinics, between the lay members responsible for raising the money and administering the clinic and the medical staff responsible for the care and well-being of the patient. As a tentative suggestion, control of the clinic might well be invested in a 'Management Committee' on which both are represented.

There are two main types of clinics for cerebral palsied children. The Diagnostic Clinic makes a full assessment of the problems of the child and his family and of the best ways of dealing with these problems. The Treatment Clinic provides treatment and continued supervision.

DIAGNOSTIC CLINICS

The Diagnostic or Assessment Clinic must be in charge of someone specially interested in cerebral palsy, and must have access to specialist departments of a general hospital, including psychology, psychiatry, neurology (including E.E.G., neuroradiology, neurosurgery), orthopaedics, electromyography, clinical pathology and biochemistry.

Because the cerebral palsied child may present so many medical, social and psychological problems, the leader of the medical team would usually be a paediatrician with, of course, a special interest in cerebral palsy. Whether neurologists, physical medicine specialists and others will work regularly in the diagnostic clinic will depend on local tastes.

Every child will be seen by a specially experienced psychologist, and it is desirable that every family should be seen by a children's psychiatrist. The Almoner is an important member of the team.

Liaison with local school services will be promoted if a liaison officer from these services can work with the clinic.

The secretarial work is usually heavy because so many specialists, authorities and agencies have to be mobilised and co-ordinated for the best care of the child.

The successful functioning of a clinic for cerebral palsied children will depend upon its geographical position, particularly in regard to the need for a recognised diagnostic centre to serve a clinical area. The clinic can, with advantage, be conducted in the children's outpatient department of a major general hospital (or in a children's hospital) where other medical services are readily available and where the diagnostic centre will easily become known to paediatricians, general practitioners and the various local authorities in the region. The arrangement will probably favour easy access and the provision of clerical assistance, medical social workers, and proper records.

It will probably be uneconomical to have more than one high level diagnostic clinic in each N.H.S. Region. It is difficult to say how often such a clinic would have to meet. In the S.E. Metropolitan Region the clinic at Guy's Hospital has a waiting-list, despite meeting twice a month. The clinic at Bristol requires two sessions weekly for diagnostic and follow-up purposes for a population of 150,000 to 200,000 children.

TREATMENT CLINICS

Each treatment clinic should be regarded as a functional unit and the services offered should bear a close relation to the needs of that particular area and also to the abilities of the clinic's staff. Its work must of course be related to that of the diagnostic clinic. It is essential that the staff of the diagnostic clinic should watch the effects of the recommendations they make and improve their diagnostic skills by continuous follow-up studies. The clinics will not necessarily be geographically near each other, however. The diagnostic clinics would probably be most conveniently situated in or near a general hospital, whereas the first essential of treatment clinics is that they should be within easy reach of the children who will need to attend frequently, perhaps daily, and for long periods.

The treatment clinics should provide general medical services, physiotherapy, occupational therapy, speech therapy, training for partially deaf children, social training and psychotherapy. Part of their work should be to help to educate the parents in the best ways of handling the child.

For children under school age the clinic will probably be an outpatient one. A nursery school unit is desirable, where children can have school training as well as physiotherapy,

speech therapy, etc. This is probably preferable to a unit which provides only treatment in a strict sense. Already some units provide such nursery-school facilities. If trained staff are difficult to obtain, the use of the clinic as a social centre where the children can meet one another once or twice a week, while their parents are relieved of their care for several hours, will fill a real need.

The organisation of a centre for small children will be the subject of co-operation between voluntary bodies, local authorities, education and health services and local consultants in paediatrics and other services. It should be noted that, while administratively the age of 5 years is a dividing line, in planning the best care of an individual child, his or her emotional, intellectual, speech and motor age may also have to be considered.

For children of school age it is most convenient to have the clinic attached to their school. If there are only a small number of children, instead of setting up a special cerebral palsy treatment unit, it may be more economical to set up a special section or class in a physically handicapped school. In a highly populated area it is probably better to have a cerebral palsy unit.

For some children there are advantages in residential observation and treatment.

Physiotherapy should be available at every type of treatment clinic. It should be under the supervision of a specialist in physical medicine. The physiotherapist must have had some experience and special training in the care of cerebral palsied children, and interest and enthusiasm should be encouraged by assisting visits to other clinics and centres. The number and length of treatment sessions for each child should be decided by the doctor in charge and other members of the team, in consultation with the physical medicine specialist and the physiotherapist. Probably all treatment sessions should last about 30 minutes. Parents should be admitted regularly to watch the treatments and be shown what to do with the child at home.

Occupational Therapy is different from diversional therapy. For the cerebral palsied child it can provide a most valuable service in teaching the techniques of eating and writing, and in other ways it helps him to be more easily accepted socially. In some centres such training is done by other workers.

Speech Therapy and Training for Partially Deaf Children should be available at least for children of three years and upwards, and treatment sessions should be of adequate length and frequency, as decided by the medical officer and other members of the team, and the speech therapist or teacher of the deaf, in consultation. Wherever possible children with cerebral palsy should be examined for partial hearing defects at a specialist audiology unit before the age of two years; simpler testing should be done from the age of six months or shortly after.

Periodic Ophthalmological Testing is wise; partly because many cerebral palsied children have been premature and as such are liable to various visual defects; partly because refractive errors appear or change during growth; partly because present research suggests that some disorders of perception may be linked with failure to develop normal eye movements.

Teaching, in the scholastic sense, may not be necessary at all clinics; if it is to be provided, daily attendance of the children should be the aim; even then, owing to interruptions for treatment, actual educational time will be much less than that available in ordinary schools. Since most centres will provide for children of very mixed ages and intelligence, all teaching will need to be individual. From the age of three to four years, social contact with other children is a *sine qua non* of growing up and is needed by the cerebral palsied child as much as by his more fortunate fellows. It may well be found that occupational therapy and diver-

sional activity, which can be offered to the older retarded cerebral palsied child as well as to these younger children not yet ready for school, may be of greater all round benefit than set school teaching. In this connection co-operation with the occupational therapist and the physiotherapist is of great value in arranging for work to be done involving movements which will help treatment.

Some clinics may be specially fortunate in obtaining the services of a teacher expert in special educational methods. There is an enormous field for ingenuity in teaching methods and in the detection of the abilities and aptitudes of the individual child, and related to this is the capacity of the teacher to develop special ways of reaching the child's mind at both perceptual and conceptual levels. The recognition of the particular ways in which learning can best be acquired requires perhaps the greatest art in the teacher, so that the necessary special educational methods can be made available. The personality of the teacher is most important. Many children with cerebral palsy are very sensitive to minimal disturbing influences and inhibitions; fears can easily be engendered and aggravated. Teachers and 'housemothers' play an important joint role in helping children over such difficulties.

Accommodation and Facilities for Treatment Clinics

The atmosphere of the treatment clinic should be as informal and free as possible. It is desirable to avoid hospital formalities. Nurses and reception clerks should be of a 'motherly type' and should not wear white coats or obvious uniform; coloured house coats or aprons are best for those handling the children. The whole atmosphere should be restful without fuss but radiating confidence.

A house with a garden can be adapted for this kind of clinic, and it is a satisfactory arrangement to choose one close to a children's hospital. The house should be on a level site with the absolute minimum of steps outside. As a general rule the working space should be at ground level, and there should be easy access for motor transport. If the rooms are on more than one floor there should be a lift. The corridors and doorways need to be wide enough to allow for wheel-chair traffic and for handrails. Shallow stairs are an advantage. The rooms should be quiet, cheerfully decorated and well warmed.

There should be some ground-floor rooms suitable for conversion into cloak-rooms and lavatories of more than average size, sufficient to provide for both the children and their parents. A special type of lavatory with back and side support may be needed for young and heavily handicapped children.

Floor coverings should permit free movement by children who can crawl or find their own way about by other methods.

Other facilities include:—

Large airy room for physiotherapy. This room should always be warm. The only special equipment required is: one or more large wide (at least 5 ft. × 3 ft.) treatment plinths, a set of practice stairs with rail and parallel bars, a large mirror reaching to the floor, and a one-way window for mothers and others to observe the progress of their children.

Small very quiet room for speech therapy. This should be internally soundproofed.

Large room for occupational training, including training in feeding, dressing, washing, etc.

Rest rooms for children: 'li-los' on the floor are good.

Dining-room: The only special equipment needed here is a supply of chairs of different sizes, preferably made of wood to permit small alterations and adaptations.

The staff will include people who visit the treatment clinic regularly and other people whose services are available on call.

Medical Staff Visiting Regularly

1. '*Specialist on Cerebral Palsy.*' He supervises treatment, visiting frequently, at least once a week. The 'specialist' may be a paediatrician, physical medicine specialist, orthopaedic surgeon, etc., or a public health service doctor.

2. *General Practitioner*, for day to day medical care.

3. *Paediatrician* (if the doctor in charge is not a paediatrician), visiting at regular intervals; and at least twice a term for diagnostic and other advice.

4. *Physical Medicine Specialist*, one of whose functions is to keep up the enthusiasm of the physiotherapists. He also must visit at least twice a term.

5. *Psychiatrist* with training in child psychiatry and, if possible, a special interest in handicapped children, visiting regularly. The psychiatrist's function would include helping all the clinic personnel to understand the emotional needs of the children and their parents, the ways of meeting these needs in the day-to-day handling in the treatment centre, and ways of recognising when the parents and/or children require to be referred to the psychiatrist for diagnostic and/or therapeutic consultation.

It would be for the psychiatrist to decide whether psychiatric and psychological treatment of individual children would be done at the unit or at his child guidance clinic. The child guidance clinic to which children are referred must be able and willing to provide psychotherapy or remedial therapy if this is necessary.

Ancillary Medical Staff Visiting Regularly

1. *Physiotherapists.*

2. *Speech Therapists.*

3. *Occupational Therapists.*

These will all, of course, attend regularly whenever the clinic is open.

The particular uses made of these services—physiotherapist, speech therapist, occupational therapist—will be carefully considered in each clinic with each case, and it should be understood that the ancillary medical staff works with, and is under the guidance and advice of, the medical team. Each ancillary worker must keep good and clear records of what progress is being achieved. All physiotherapists working with cerebral palsied children should have a special interest in this work and must have special experience and training in all aspects of the problems presented. Much ingenuity may be introduced in these various special procedures, and much will depend not only on the particular techniques but on the ability to get the child into a receptive stage. Impatience, on the other hand, has great inhibiting effects. Everyone concerned with cerebral palsied children must have a slow persistence and must learn to accept even minimal and gradual improvement as adequate in some clinical circumstances.

Teaching Staff

If the clinic undertakes functions as a school or nursery school, teachers will also attend whenever the school is open. Such teachers should, if possible, have attended at least one short course on physically handicapped or E.S.N. children, or, in future, one of the projected courses (under N.S.S. auspices) for teachers of cerebral palsied children.

Psychologists

An educational psychologist, who will give general guidance to clinic personnel on educational matters and also advise on educational needs of specific children, and, where necessary, give remedial teaching. In addition to the usual recognised qualifications, the

educational psychologist should have special knowledge, experience and interest in handicapped children. His or her functions are two-fold: assessment of children's assets and handicaps in learning in the broadest sense, and guidance on the educational needs of specific children. Sometimes the psychologist would help the teaching staff on the problems of teaching individual children, and sometimes he or she would undertake remedial teaching. Moreover, psychologists usually have an interest in and a contribution to make to research.

Social Worker (or Psychiatric Social Worker)

It is important, in order to promote good treatment as well as complete diagnosis, that the social worker's appointment should be more or less full-time, so that she may make contacts with the homes, advise on handling children and their families, and in general act as a link between the diagnostic-treatment clinic(s) and the families concerned. Interest in and knowledge of handicapped children is essential. The social worker should have had opportunities of learning about cerebral palsy and its problems before taking up work in these units. This is particularly desirable because some of the parents' anxieties are proper and some are due to misunderstandings about the child's actual handicap(s). It is also important that she should have a knowledge of the various emotional difficulties that beset cerebral palsied children and their parents so that she may mobilise for them the help of the psychiatrist.

In the more local type of clinic the organisation may have to have some different arrangements in regard to staff. For instance, it would be more essential to have a good and well-interested general practitioner at the clinic to keep an eye on the place; he could also encourage his other local practitioner colleagues to be aware of the work of the clinic. Any clinic can also be an occasional meeting-place for discussion with L.A. and L.E.A. staff and parents and possibly school teachers and medical auxiliary workers.

All members of the staff, with the paediatrician, the physical medicine and orthopaedic specialists, the ancillary medical staff, and the psychologists and social workers, should forgather about every three months, or more often, to discuss cases and the progress of the clinic and individual children. The services of the area or regional diagnostic clinic should be fully available and in close liaison with all treatment centres.

Other Staff of the Clinic

House-Mothers. House-mothers are important because they give emotional support to children when their parents are not there. In some cases parents will act as house-mothers at clinics.

Domestic Help. This will include housekeepers, cook, cleaners and also helpers to dress and undress the children, help at meals and attend to toilet needs. Some of these people may be voluntary and untrained: some may be parents.

Clerical Help. The organisation of clinics and the maintenance of contacts with medical and educational services may involve a good deal of clerical work.

Other Helpers. It is often extremely useful to have a carpenter on the staff. A handyman, able to lift heavier children and perhaps act as a driver, is also very useful.

Transport. The expenses of transport may be very high and need earnest consideration in planning for a treatment clinic.

Nearby children may be brought by the parents on foot or using a push-chair. Some children will be able to come by ordinary public transport. The clinic is best placed where several bus routes meet. Hospital car services and ambulances may help. The clinic's own car service may be a good solution but can be expensive.

RECORDS

Accurate and comprehensive records should be kept of the findings of the diagnostic clinic, of the treatments administered and of the child's continuous development in the treatment clinic. This is important not only for the wise guidance of treatment but also for research purposes.

The record system is likely to vary from clinic to clinic according to the views of the individual teams. The clinic should maintain its own set of records in an easily accessible index system. A folder for each child should contain all reports, including the medical, psychological and social reports.

The Medical Records should contain a complete history of: family, previous pregnancies, pregnancy, labour (anaesthetic, etc.), conditions immediately after birth and in the perinatal period and after, birth weight, early weeks and months, milestones, course of the handicap; complete physical examination by paediatrician, and special notes by physical medicine specialist, orthopaedic surgeon and others; psychiatric, intellectual, and educational assessment.

The Psychological Records should include findings of any tests administered; developmental observations, notes on behaviour in psychological sessions and comments on the child's educational status, requirements, and special needs.

The Social Worker's Report should take into account the social circumstances of the family, and the relationships of the family, to one another and particularly towards their cerebral palsied child, and should attempt to evaluate the emotional climate as it affects this child, favourably or unfavourably. It should also assess how much personal support the parents require.

Postscript. The question of planning research projects, and the use of clinic records for research purposes, will be discussed later in a special paper to be published in *The Cerebral Palsy Bulletin*.

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